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ABSTRACT

The guide is intended to help parents of young children with special needs identify early intervention services (for children birth through age 2) and special education services (for children ages 3 through 5). Part 1 answers typical questions of parents of infants including: What should I do if I think my child has special needs? What are early intervention services? Who do I contact first for help? What is an assessment? Who pays for the assessment? How can I find out more about special education laws? Part 2 answers similar questions of parents of preschoolers with handicaps: What should I do if I think my preschool child needs special education? Will I have to pay for the assessment or for services? Are there any parent groups in my area? Part 3 provides answers to similar questions about programs and services for rural, adoptive/foster, and military families and their young children with handicaps. Next, a glossary defines about 50 special education terms. Also included are a sample record-keeping worksheet, information on the Education for All Handicapped Children Act and the Education of the Handicapped Act Amendments of 1986, a listing of federally funded parent programs, and an annotated bibliography of 12 recommended readings. (DB)

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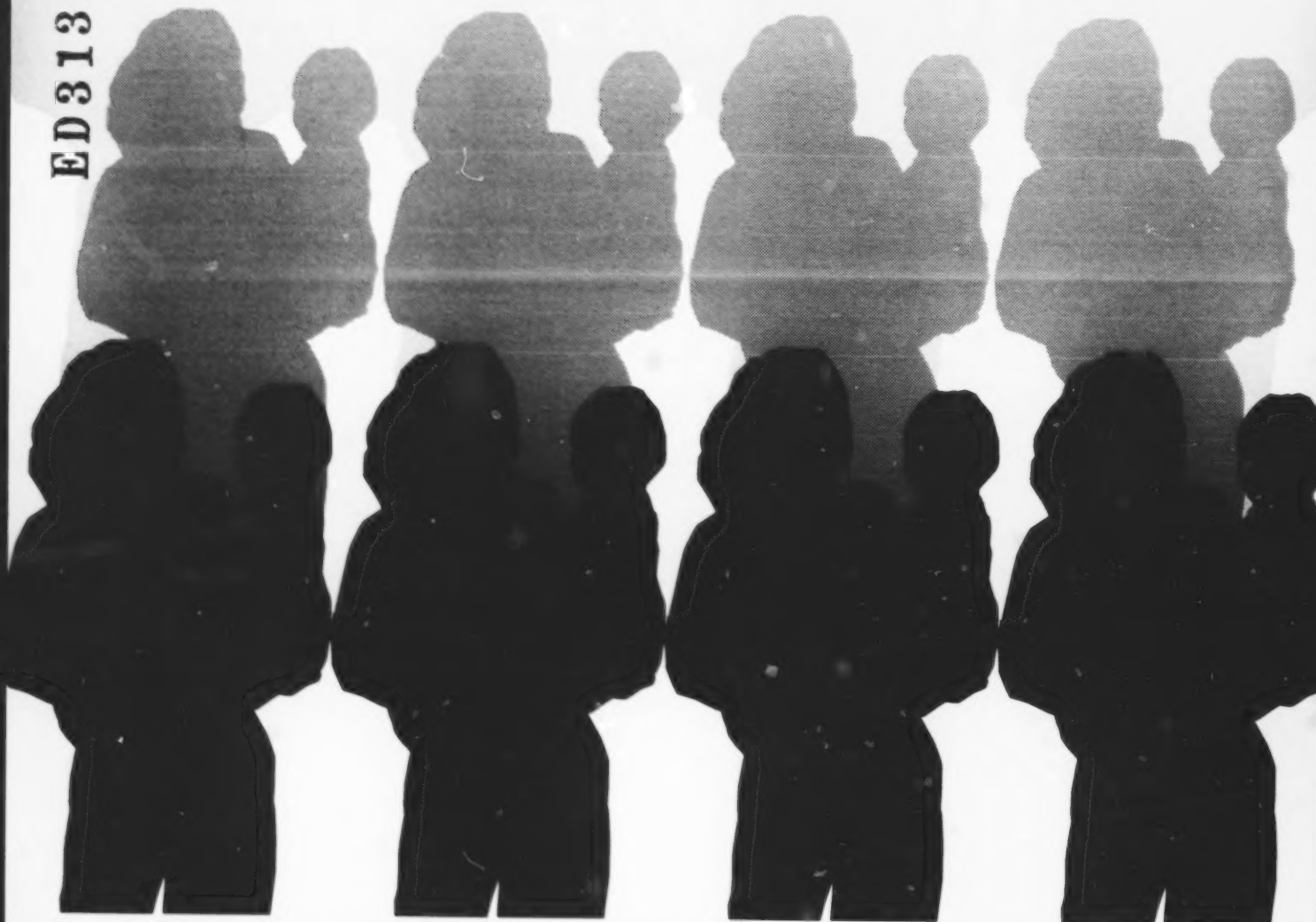

A PARENTS' GUIDE

TO ACCESSING PROGRAMS FOR INFANTS, TODDLERS, AND PRESCHOOLERS WITH HANDICAPS

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NICHCY

National Information Center For Children And Youth With Handicaps
P.O. Box 1492 Washington, D.C. 20013

Thank you for contacting the National Information Center for Children and Youth with Handicaps (NICHCY). We have written this information to help parents and guardians of young children with **special needs** * (ages birth through 5 years) learn how to get help for their children.

We have tried to answer some of the questions you may have about **early intervention services** for children ages birth through 2 years old and **special education services** for children ages 3 through 5 years old. We have also included lists of people and places to contact for more information.

BEFORE YOU TURN THE PAGE, PLEASE READ THE INFORMATION BELOW:

The rules or guidelines for **special education** in the United States and its territories are outlined in a federal law known as **Public Law(P.L.)94-142.** Each state or territory develops its own **policies** for carrying out **P.L.94-142.** (You can read more about this law in Attachment A.)

You'll need to find out what the **early intervention** or **special education policies** are in your state or area. The lists of agencies and contact people in your state should help you get started. (See Attachments B and D.)

FOR ANSWERS TO QUESTIONS ABOUT **EARLY INTERVENTION SERVICES** FOR CHILDREN BIRTH THROUGH 2 YEARS OLD.....READ PART 1

FOR ANSWERS TO QUESTIONS ABOUT **SPECIAL EDUCATION SERVICES** FOR CHILDREN 3 THROUGH 5 YEARS OLD.....READ PART 2

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* Note: The phrases "children with **special needs**" or "**special needs** children" are used throughout this document to refer to children who have **handicaps** or who are **at risk** for developing **handicaps.**

Words in bold are defined in the Parents' Dictionary that begins on page 12.

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PART 1:

QUESTIONS AND ANSWERS

ABOUT

EARLY INTERVENTION SERVICES FOR INFANTS AND TODDLERS WHO HAVE HANDICAPS OR ARE AT RISK FOR DEVELOPING HANDICAPS

(AGES BIRTH THROUGH 2 YEARS OLD)

NOTE: Words that appear in **bold** are words that are commonly used in **special education.** Many may be new to you. We have used these terms to help you become familiar with them. You can look up their definitions in the Parents' Dictionary that begins on page 12.

We have used the term "parents" to mean anyone who is in charge of the care and well-being of a child. These can be guardians, single parents, grandparents, surrogate parents, or foster parents.

Below are answers to questions parents often ask about **early intervention services** for infants and toddlers (ages birth through 2 years) who have **handicaps** or are **at risk** for developing **handicaps.**

A new federal law known as **Public Law(P.L.)99-457** guarantees certain rights to young children (ages 0 to 5) with **special needs.** This law is the most recent **amendment** to **Public Law (P.L.)94-142.** (To learn more about both of these laws, see Attachment A.) Some states already provide **services** to children with **special needs** (ages 0 to 5); other states will follow no later than school year 1991-1992.

To find out more about your rights in getting **early intervention services** for your child, please read on .....

Q: WHAT SHOULD I DO IF I THINK MY CHILD HAS SPECIAL NEEDS?

A: First, you'll need to find out if your infant or toddler is **eligible for early intervention services.** There are many people who can help you with this. We will explain how to get the help you need in the pages that follow.

Q: WHAT ARE **EARLY INTERVENTION SERVICES?**

A: These are **services** for infants and toddlers that are designed to identify and treat a problem or delay as early as possible. **Early intervention services** are offered through a **public agency** and are provided in different settings, such as the child's home, a clinic, a neighborhood center, or the local health department.

Early intervention services can range from prescribing glasses for a two-year-old to developing a complete **physical therapy** program for an infant with cerebral palsy.

Q: WHOM DO I CONTACT FIRST FOR HELP?

A: Each state decides which of its agencies will be the **lead agency** in charge of **early intervention services** for infants and toddlers with **special needs.** In your state, the first contact person may be an **early childhood specialist,** someone with the **lead agency**, or someone in your state's **Child Find** office.

To find out who can help you, call your local elementary school or local school district office and ask for the person in your area who is in charge of **programs** for infants and toddlers with **special needs.**

Or, contact the person listed under "Programs for Infants and Toddlers with Handicaps" listed on your State Resource Sheet (Attachment D). Explain to whomever you talk to that you want to find out about **early intervention services** for your child.

Write down the names and phone numbers of everyone you talk to. (You can use the Sample Record-Keeping Worksheet at the bottom of page 16 as a guide.) Having this information available may be helpful to you later on.

Q: WHAT DO I SAY WHEN I TALK TO MY LOCAL CONTACT PERSON?

A: Explain that you think your child may need **early intervention services** and you would like to arrange for an **assessment.** Write down any information you are given.

Q: WHAT IS AN **ASSESSMENT?**

A: An **assessment is the** process of gathering and using information about how a child is **developing** and what kind of help he or she might need. It is a way of observing and **evaluating** a child to see if he or she is **eligible** for **early intervention services.**

This information may come from:

- Doctor(s') reports;
- Results from **developmental tests** given to your child;
- Your child's medical history;
- Observations and feedback from all members of the **assessment team,** including parents; and
- Any other important observations, records, and/or reports about your child.

Q: WHO DOES THE **ASSESSMENT?**

A: It depends on your state's **policies** or rules. Ask your local contact person about this. Usually, a team of professionals which may include a **psychologist,** an **early childhood specialist,** and an **occupational** or **physical therapist** will test a child.

Q: WHO PAYS FOR THE **ASSESSMENT?**

A: Under **P.L.99-457, assessments** are provided at no cost to families. Check with your contact person for local guidelines.

Q: WILL I HAVE TO PAY FOR ANY **SERVICES** MY CHILD IS FOUND **ELIGIBLE** FOR?

A: You may or may not have to pay for some **services,** depending on your state's **policies.** Check with the contact person in your area or state. Some **services** may be covered by your health insurance or by Medicaid.

Generally, they are provided at no charge. In some areas, however, you **may be** charged a "**sliding-scale**" fee that is based on what you earn. Every **effort is** made to **provide services** to all infants and toddlers who need **help, regardless of family** income.

Q: **ARE THERE** ANY **PARENT** GROUPS IN MY AREA THAT CAN GIVE **ME MORE** INFORMATION ABOUT **EARLY INTERVENTION SERVICES?**

A: **There** are several **types of parent** groups, including:

- **Support groups (such as Parent-to-Parent)** for families of children **with handicaps;**
- **Parent training and information programs** funded by the federal **government, such as** the Technical Assistance for Parent Programs **[TAPP] Project; and**
- **Groups concerned with** a specific **handicap,** such as United Cerebral **Palsy Associations,** Inc. (UCPA) or the Association for Retarded **Citizens of** the United States (ARC).

We have listed some of these groups on your State Resource Sheet in Attachment D. Others are on the list of Federally Funded Parent Programs in Attachment B. (If your state or territory is not listed there, see the "TAPP Project Regional Centers" list [also in Attachment B] and look under "Area Served.")

Parent groups can offer information, support, and/or training to families of children with **handicaps** to help parents take a more active role in helping their children. Through such groups, families meet other families with similar needs to discuss resources, day-to-day problems, and personal insights.

Someone at your local school or at your state or regional parent center may be able to tell you about nearby groups. For more details on parent groups, contact NICHCY and ask for our "Parent Pack."

Q: I STILL HAVE A LOT OF QUESTIONS. HOW CAN I FIND OUT MORE ABOUT **SPECIAL EDUCATION** LAWS AND ABOUT **EARLY INTERVENTION SERVICES?**

A: See Attachment A for more information on two important **special education** laws. Also, see the "References" section in Attachment C for information on the development of infant and toddlers with **handicaps,** on early intervention programs and services, and on raising and caring for a young child with **special needs.**

Once your child has been found **eligible** for **early intervention services,** your family will be assigned a **case manager.** As time goes on, you will probably have more questions. For example, you might want to know:

- How do I check on the **services** my child is getting?
- What do I do if I am not satisfied with my child's **assessment, program,** or progress?
- What happens to my child once he/she is too old for the **program**?
- What about **private therapists** and private schools?

For answers to these and other questions, talk to your **case manager** or contact a **parent support** and/or training group in your area (Attachment B).

We hope these materials are useful. If you need more help or information from NICHCY, please call us (toll free) at 1-800-999-5599 or write us at this address:

NICHCY
Box 1492
Washington, D.C. 20013

PART 2:

QUESTIONS AND ANSWERS

ABOUT

SPECIAL EDUCATION PROGRAMS AND SERVICES FOR PRESCHOOLERS WITH HANDICAPS

(AGES 3 THROUGH 5 YEARS OLD)

NOTE: Words that appear in bold are words that are commonly used in special education. Many may be new to you. We have used these terms to help you become familiar with them. You can look up their definitions in the Parents' Dictionary that begins on page 12.

We have used the term "parents" to mean anyone who is in charge of the care and well-being of a child. These can be guardians, single parents, grandparents, foster parents, or surrogate parents.

Below are answers to questions people often ask about special education programs and services for preschool children ages 3 to 5 years old who have handicaps or who are at risk for developing handicaps.

A new federal law known as Public Law(P.L.)99-457 guarantees certain rights to young children (ages 0 to 5) with special needs. This law is the most recent amendment to Public Law(P.L.)94-142. (You can learn more about both of these laws in Attachment A.) Some states already provide services to young children ages birth to 5 years; other states will follow no later than school year 1991-1992.

To find out more about your rights in special education and getting services for your child, please read on....

Q: **WHAT SHOULD I DO IF I THINK MY PRESCHOOL CHILD NEEDS SPECIAL EDUCATION?**

A: If you think your preschooler needs special education, you will first want to find out if he or she is eligible for a special education program. There are people who can help you with this. Read on and we will explain how to contact them.

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*Note: The phrases "special education," special education programs," "special education services," and "special education programs and services" are used interchangeably in this section.

Q: WHAT ARE SPECIAL EDUCATION PROGRAMS?

A: **Special education programs** are **specially designed** programs in public schools offered at no cost to families **for children with handicaps**. In some public schools, children ages 3-5 **with handicaps** already can receive special **education services** under **P.L.94-142.**

Today, under **P.L.99-457,** most, if **not all, schools** must offer special **education services** to **eligible** 3-5-year-**olds with handicaps** no later than school year 1991-92.

Q: WHOM DO I CONTACT FIRST FOR HELP?

A: The best place to start is your local public elementary school. (In most cases, this would be the school in your neighborhood.) Call and ask to speak to the principal or to someone in charge of **special education** at the school.

Or, look on your State Resource Sheet (Attachment D) under "State Department of Education" for the early childhood or preschool specialist for children (ages 3-5 years) or for the person listed there who would most likely be able to help you or could refer you to the appropriate person. Explain to whomever you talk to that you want to find out **about special education services** for your child. Ask what you need to do **to arrange** for an **assessment.**

Write down the names and phone numbers **of everyone you talk to.** (You can use the Sample Record-Keeping Worksheet **at the bottom of page** 16 as a guide.) Having this information available may **be helpful to you later** on.

Q: WHAT IS AN ASSESSMENT?

A: An **assessment** is the process of gathering and using **information about** your child's development and the kind of help he or **she might need.** It is a way of observing and **evaluating** your child to see if **he or she is eligible** for **special education services.**

This information may come from:

- Doctor(s') reports;
- Results from **developmental tests** given to **your child;**
- Your child's medical history;
- Observations and feedback from all members **of the assessment team,** including parents; and
- Any other important observations, records, **and/or reports** about your child.

Q: WHO DOES THE ASSESSMENT?

A: It depends on the rules in your state or school district. Ask your school contact person what the policy is for getting an assessment for your child.

Q: WILL I HAVE TO PAY FOR THE ASSESSMENT OR FOR ANY SERVICES MY CHILD MAY BE ELIGIBLE FOR?

A: In general, special education services either are already or should be offered for 3-5-year-olds at no cost to parents no later than school year 1991-92. The assessment generally is considered part of these services.

Assessments given by a school district are provided at no cost to families.

Q: ARE THERE ANY PARENT GROUPS IN MY AREA THAT CAN GIVE ME MORE INFORMATION ABOUT SPECIAL EDUCATION?

A: There are several types of parent programs, including:

- Support groups (such as Parent-to-Parent) for families of children with handicaps;
- Parent training and information programs funded by the federal government, such as the Technical Assistance for Parent Programs [TAPP] Project; and
- Groups concerned with a specific handicap, such as United Cerebral Palsy Associations, Inc. (UCPA), or the Association for Retarded Citizens of the United States (ARC).

We have listed some of these groups on your State Resource Sheet in Attachment D. Others are on the list of Federally Funded Parent Programs in Attachment B. (If your state or territory is not listed there, go to the "TAPP Project Regional Centers" list [also in Attachment B] and look under "Area Served." Someone at your state regional center should be able to tell you about other parents programs in your area.) You can also check with someone in your local school district or at your local school.

Parent groups can offer information, support, and/or training to families of children with handicaps to help them take a more active role in their children's education. Through such groups, families meet other families with similar needs to discuss local resources, daily problems, and personal insights. For more details on these and other parent groups, contact NICHCY and ask for our "Parent Pack."

Q: I STILL HAVE A LOT OF QUESTIONS. HOW CAN I FIND OUT MORE ABOUT SPECIAL EDUCATION PROGRAMS AND SERVICES?

A: See Attachment A to learn more about two important special education laws. Also, see the "References" section in Attachment C for information on raising and caring for a young child with special needs.

Once your child has been found eligible for special education, you will most likely have more questions. For example:

- How do I check on my child's special education program?
- What do I do if I am not satisfied with my child's assessment, placement, program, or progress?
- What happens to my child when he/she is too old for the program?
- What about private therapists and private schools?

For answers to these and other questions, talk to your special education coordinator or school principal or contact a parent support and/or training group in your area (listed in Attachment B).

Also, write to NICHCY and ask for our "Legal Pack." It contains information about special education laws and parents' rights in getting school services for their children with handicaps.

We hope these materials are useful. If you need more help or information from NICHCY, please call us (toll free) at 1-800-999-5599 or write us at this address:

NICHCY
Box 1492
Washington, D.C. 20013

PART 3:

QUESTIONS AND ANSWERS

ABOUT

PROGRAMS AND SERVICES

FOR RURAL, ADOPTIVE/FOSTER, AND MILITARY FAMILIES AND THEIR YOUNG CHILDREN WITH HANDICAPS

Q: WHAT ABOUT SERVICES FOR FAMILIES IN REMOTE OR RURAL AREAS?

A: The goals of early intervention or special education programs and services for young children with special needs is the same for both rural and urban families. However, the ways in which these services are offered may be different. One group that may be able to offer information specifically about services for rural families is:

American Council on Rural Special Education (ACRES)
Western Washington University
359 Miller Hall
Bellingham, Washington, 98225
(206) 676-3576

ACRES is a national organization of professionals and parents who work together to improve services in rural areas to children with handicaps. ACRES publishes many useful materials, including a State Department of Education "Rural Representatives Directory" which lists the names of people at the state level you can contact.

Q: WHAT ADDITIONAL INFORMATION DO FAMILIES OF ADOPTED OR FOSTER CHILDREN WITH HANDICAPS NEED ABOUT EARLY INTERVENTION OR SPECIAL EDUCATION SERVICES ?

A: In general, the process for getting early intervention or special education programs and services for legally adopted children with special needs is the same as it is for all children with special needs.

An organization that has a nationwide family support network of adoptive families is OURS (Organization for United Response). While the main focus of this organization is to provide general help and information to all adoptive families, its bimonthly parent support magazine includes information and resources for families of adopted children who have special needs . (You can write to them for an index of OURS magazine articles.)

The address for OURS is :

The Organization for United Response (OURS), Inc.
3307 Highway 100, North, Suite 203
Minneapolis, MN 55422
(612) 535-4829

Families that provide foster homes to children who have handicaps or who are at risk of developing handicaps may want to contact the National Foster Parent Association, Inc. (NFPA). This national, non-profit group offers information and support to all foster parents. Members of the group receive a bimonthly newsletter and nine issues of the Foster Care Journal. They are also able to use all NFPA resources.

For membership information, contact:

National Foster Parent Association, Inc. (NFPA)
P.O. Box 12131
San Francisco, CA 94112

For the Information/Services Office of NFPA, contact:

Gordon Evans
National Foster Parent Association, Inc.
Information/Services Office
226 Kilts Drive
Houston, TX 77024
(713) 467-1850

Q: **HOW DO I FIND OUT ABOUT PROGRAMS AND SERVICES FOR MILITARY FAMILIES WHOSE YOUNG CHILDREN HAVE SPECIAL NEEDS?**

A: One way is through a project known as Specialized Training of Military Parents (STOMP). This organization provides information and help to military families (both in the U.S. and overseas) who have children with special needs.

The STOMP staff is made up of parents of children with special needs who are trained to work with other parents of children with special needs. As spouses of members of the military, the staff understands the unique needs of military families.

To contact STOMP, call or write:

Specialized Training of Military Parents (STOMP)
1851 Ram Runway, Suite 102
College Park, GA 30337
(404) 767-2258

OR

Specialized Training of Military Parents (STOMP)
12208 Pacific Highway, SW
Tacoma, WA 98499
(206) 588-1741

(Call either number collect if you are a member of a military family.)

Another way to learn more about early intervention and special education programs and services for children in military families stateside is to contact the Community Service Center (also called Family Service Center or Family Resource Center) or the assigned community contact person on your installation.

While most children of military families attend (or will attend) public schools, some are in Section VI schools. Each Section VI school will follow its own state's plan for planning programs under P.L. 99-457. If you need more information, call or write the contact person in your state education agency. (See your State Resource Sheet in Attachment D.)

The office of Department of Defense Dependent Schools (DODDS) overseas issues a handbook for military families with children who have special needs and are receiving, or are eligible to receive, a free, appropriate public education through DODDS overseas. (At present, DODDS overseas has 36 programs for preschool children with handicaps [ages 3-5].) To order the handbook, write to:

Department of Defense Dependent Schools (overseas)
Special Education Coodinators
2461 Eisenhower Avenue
Alexandria, VA 22331-1100

PARENTS' DICTIONARY OF TERMS USED IN

SPECIAL EDUCATION *

* **Note:** The following definitions have been compiled from a variety of sources. The contents of this dictionary do not necessarily represent definitions endorsed by the U.S. Department of Education.

advocate - someone who takes action to help someone else (as in "educational advocate"); also, to take action on someone's behalf

amendment - a change, revision, or addition made to a law

appeal - a written request for a change in a decision; also, to make such a request

appropriate - able to meet a need; suitable or fitting; in special education, it usually means the most normal setting possible

assessment - a collecting and bringing together of information about a child's learning needs, which may include social, psychological, and educational evaluations used to determine assignment to special programs or services; a process using observation, testing, and test analysis to determine an individual's strengths and weaknesses to plan his or her educational services

assessment team - a team of people from different areas of expertise who observe and test a child to find out his or her strengths and weaknesses

at risk - a term used with children who have, or could have, problems with their development that may affect later learning

case manager - someone who acts as a coordinator of an infant's or toddler's services and works in partnership with the family and providers of special programs; case managers are employed by the lead agency

Child Find - a service directed by each state's Department of Education for identifying and diagnosing unserved children with handicaps; while Child Find looks for all unserved children, it makes a special effort to identify children from birth to six years old

cognitive - a term that describes the process people use for remembering, reasoning, understanding, and using judgement

counseling - advice or help given by someone qualified to give such advice or help (often psychological counseling)

developmental - having to do with the steps or stages in growth and development before the age of 18

developmental history - the developmental progress of a child (ages birth to 18 years) in such skills as sitting, walking, or talking

developmental tests - standardized tests that measure a child's development as it compares to the development of all other children at that age

due process (procedure) - action that protects a person's rights; in special education, this applies to action taken to protect the educational rights of students with handicaps

early childhood specialist - someone who specializes in early childhood development, usually having a Master's degree or Ph.D in an area related to early childhood education and/or development

early intervention policies - see policy/policies

early intervention services or programs - programs or services designed to identify and treat a developmental problem as early as possible

eligible - able to qualify

evaluating - analyzing a child's special learning needs

evaluation - (applies to school-aged children); a way of collecting information about a student's learning needs, strengths, and interests; the evaluation is part of the process of determining whether a student qualifies for special education programs and services

free, appropriate public education [often referred to as FAPE] - one of the key requirements of Public Law 94-142, which requires that an education program be provided for all school-aged children (regardless of handicap) without cost to families; the exact requirements of "appropriate" are not defined, but other references within the law imply the most "normal" setting available

handicap - the result of any physical or mental condition that affects or prevents one's ability to develop, achieve, and/or function in an educational setting at a normal rate

identification - the process of locating and identifying children needing special services

Individualized Education Program (IEP) - a written education plan for a school-aged child with handicaps developed by a team of professionals (teachers, therapists, etc.) and the child's parents; it is reviewed and updated yearly and describes how the child is presently doing, what the child's learning needs are, and what services the child will need; (For children ages 0-2 years, the IFSP is used.)

Individualized Family Service Plan (IFSP) - a written statement for an infant or toddler (ages birth through 2 years old) developed by a team of people who have worked with the child and the family; the IFSP must contain the child's level of development, strengths and needs, major goals or outcomes expected, services needed, date of the next evaluation, and the starting date of the present IFSP

lead agency - the agency (office) within a state or territory in charge of overseeing and coordinating early childhood programs and services

Least Restrictive Environment (LRE) - an educational setting or program that provides a student with handicaps the chance to work and learn to the best of his or her ability; it also provides the student with as much contact as possible with children without handicaps, while meeting all of the child's learning needs and physical requirements

occupational therapy - a therapy or treatment provided by an occupational therapist that helps an individual develop mental or physical skills that will aid in daily living; it focuses on the use of hands and fingers; on coordination of movement; and on self-help skills, such as dressing, eating with a fork and spoon, etc.

parent training and information programs - programs that provide information to parents of children with special needs about acquiring services, working with schools and educators to ensure the most effective educational placement for their child, understanding the methods of testing and evaluating a child with special needs, and making informed decisions about their child's special needs

physical therapy - treatment of (physical) disabilities given by a trained physical therapist (under doctor's orders) that includes the use of massage, exercise, etc. to help the person improve the use of bones, muscles, joints, and nerves

placement - the classroom, program, and/or therapy that is selected for a student with special needs

policy/policies - rules and regulations; as related to early intervention and special education programs, the rules that a state or local school system has for providing services for and educating its students with special needs

private therapist - any professional (therapist, tutor, psychologist, etc.) not connected with the public school system or with a public agency

program(s) - in special education, a service, placement, and/or therapy designed to help a child with special needs

psycho-social (development) - the psychological development of a person in relation to his or her social environment

psychologist - a specialist in the field of psychology, usually having a Master's degree or Ph.D. in psychology

public agency - an agency, office, or organization that is supported by public funds and serves the community at large

Public Law(P.L.)94-142 - a law passed in 1975 requiring that public schools provide a "free, appropriate public education" to school-aged children ages 3-21 (exact ages depend on your state's mandate), regardless of handicapping condition; (also called the Education for All Handicapped Children Act)

Public Law(P.L.)99-457 - an amendment to **P.L.94-142** passed in 1986 which requires states and territories to provide a "free, appropriate public education" to all children ages 3-5 by school year 1991-92 and provides funds for states and territories to offer programs and services to infants and children (ages birth through 2 years) with handicaps

related services - transportation and developmental, corrective, and other support services that a child with handicaps requires in order to benefit from education; examples of related services include: speech pathology and audiology, psychological services, physical and occupational therapy, recreation, counseling services, interpreters for the hearing impaired, and medical services for diagnostic and evaluation purposes

services/service delivery - the services (therapies, instruction, treatment) given to a child with special needs

special education - see special education programs and services

special education coordinator - the person in charge of special education programs at the school, district, or state level

special education programs/services - programs, services, or specially designed instruction (offered at no cost to families) for children over 3 years old with special needs who are found eligible for such services; these include special learning methods or materials in the regular classroom, and special classes and programs if the learning or physical problems are serious

special needs - (as in "special needs" child) - a term to describe a child who has handicaps or is at risk for developing handicaps who requires special services or treatment in order to progress

speech/language therapy - a planned program to improve and correct speech and/or language or communication problems in people who are not thought to be able to improve without such help

Parents' "Next Step" Record-Keeping Worksheet

The sample record-keeping worksheet below can help you start a file of information about your child. As you contact different people and places, it's a good idea to keep records of whom you've talked with and what was said. As time goes on, you will want to add other information to your file, such as:

- Letters and notes (from doctors, therapists, etc.)
- Medical records and reports;
- Results of tests and **evaluations;**
- Notes from meetings about your child;
- Therapist(s') reports;
- **IFSP** and **IEP** records;
- Your child's **developmental history,** including personal notes or diaries on your child's development;
- Records of shots and vaccinations; and
- Family medical histories.

Make sure you get copies of <u>all</u> written information about your child (records, reports, etc.). This will help you become an important coordinator of **services** and a better **advocate** for your child. Remember, as time goes on, you'll probably have more information to keep track of, so it's a good idea to keep it together in one place.

SAMPLE RECORD-KEEPING WORKSHEET

Name of person or agency you talked to _____

Name of your contact person
(may be same as above) _____

Date you called_____ Phone # _____

Results of Discussion: _____
_____
_____
_____
_____
_____

Action taken
(if any):_____
_____
_____
_____
_____
_____

ATTACHMENT A

PUBLIC LAW 94-142

(The Education for All Handicapped Children Act)

Going to school and getting an education is every child's right. This is true for children with **handicaps** as well. They have the right to go to school and to learn academic and social skills in ways that meet their special needs.

To make sure that children with **handicaps** have these rights, Congress passed a law in 1975 known as **Public Law(P.L.)94-142.** This law requires that all states (and territories) provide a public school education to children, ages 3 to 21, (unless state law or practice does not provide for public school **services** for children 3-5 or 18-21), no matter how severe their **handicap(s)** are. Under **P.L. 94-142**, all children with **handicaps** have the right to learn to the best of their abilities.

There are several basic rights that this law promises to children, with **handicaps** (ages 3 to 21) and their parents:

- The right to a **"free, appropriate public education"** at public expense (in some cases, this may include placing a child in a private school);
- The right to an educational **placement** that is based on an **assessment** and **evaluation** of each child's own special needs;
- The right for children with **handicaps** to receive teaching or instruction that is designed to meet their needs; these needs are to be clearly written and included in an **Individualized Education Program (IEP)** for each child, with statements about what **services** the child will receive;
- The right to a full range of educational **services** that may include **related services** such as **counseling**, special transportation, **speech/language therapy**, or **occupational** or **physical therapy;**
- The right for parents (or guardians) to be included in making decisions about their child's educational needs and to approve the educational plans for their child; and
- The right for parents (or guardians) to **appeal** any decisions made about the **identification, evaluation**, and **placement** of the child through a **due process procedure.**

Finally, **P.L.94-142** requires that children with **handicaps** be educated in the **"Least Restrictive Environment" (LRE),** that is, in the most normal school setting possible, with special help provided.

For more information about P.L.94-142, please contact:

NICHCY
P.O.Box 1492
Washington, D.C. 20013

PUBLIC LAW 99-457

(The Education of the Handicapped Act Amendments of 1986)

In October, 1986, Congress passed a very important **special education** law called **Public Law(P.L.)99-457**. This law is an **amendment** to **P.L.94-142** and is an important step forward in educating young children with **handicaps.**

Under **P.L.99-457**, Congress has made funds available to help states and territories wanting to continue receiving federal funds under the infant, toddler, and preschool programs to provide the following **services:**

- **Early Intervention Services** to infants and toddlers (ages birth through 2 years) with **handicaps** no later than school year 1991-92. (If a state chooses to, it can also serve infants and toddlers **at risk** of developing handicaps); and
- **Special education programs** and **related services** to preschoolers (ages 3 through 5 years) who have **handicaps** no later than school year 1991-92.

The term "handicapped infants and toddlers" in **P.L.99-457** refers to children (ages birth through 2 years) who need **early intervention services** in any of the following five areas:

- Physical,
- **Cognitive,**
- **Speech** and **language,**
- **Psycho-social,** and/or
- Self-help skills.

Early intervention services must be provided by people who are qualified to work with infants and toddlers who have **handicaps** or who are **at risk** for developing **handicaps**. Any **services** provided must be written into an **Individual Family Services Plan (IFSP)** that is reviewed every 6 months.

Public Law 99-457 also assures that all the rights and protections under **P.L.94-142** extend to all preschool children (ages 3-5 years) with **handicaps**. It strengthens and expands current **programs** for preschoolers with **handicaps** (ages 3-5 years) and increases the funding available for developing and improving such **programs. Public Law 99-457** is important because it recognizes that some infants and toddlers will need **early intervention** because they already have, or most likely will have, a delay that will have an impact on future learning.

For more information about P.L.99-457, please contact:

NICHCY
P.O. Box 1492
Washington, D.C. 20013

ATTACHMENT B

Federally Funded Parent Programs

The U.S. Department of Education, Office of Special Education and Rehabilitative Services, Office of Special Education Programs funds the following parent training and information projects. These projects are designed to provide information and training to assist parents of children with handicapping conditions to be more knowledgeable participants in their children's services.

Alabama
Special Education Action Committee, Inc.
P.O. Box 81112
Mobile, AL 36689
(205) 478-1208
(1-800) 222-7322 (AL)
Director: Carol Blades

Arizona
Pilot Parents, Inc.
2005 North Central Avenue, Suite 100
Phoenix, AZ 85004
(602) 271-4012
Director: Mary Slaughter

Arkansas
Arkansas Coalition for the Handicapped
519 East Fifth Street
Little Rock, AR 72202
(501) 376-3420
Director: Paul Kelly

California
Team of Advocates for Special Kids (TASK)
18685 Santa Ynez
Fountain Valley, CA 92708
(714) 962-6332
Director: Joan Tellefsen

Colorado
Parent Education and Assistance for Kids (PEAK)
6055 Lehman Drive, Suite 101
Colorado Springs, CO 80918
(719) 531-9400
Directors: Judy Martz & Barbara Buswell

Connecticut
Connecticut Parent Advocacy Center
5 Church Lane - Suite 4
East Lyme, CT 06333
(203) 739-3089
(1-800) 445-CPAC (CT)
Director: Nancy Prescott

Delaware
PIC of Delaware, Inc.
Newark Medical Building, Suite 5
327 East Main Street
Newark, DE 19711
(302) 366-0152
Director: Patricia Frunzi

District of Columbia
Parents Reaching Out Service, Inc.
DC General Hospital
Department of Pediatrics
Fourth Floor, West Wing
1900 Massachusetts Avenue, SE
Washington, DC 20003
(202) 727-3866
Director: Gloria Stokes

Florida
Parent Education Network/Florida, Inc.
2215 East Henry Avenue
Tampa, FL 33610
(813) 238-6100
Director: Nadine Johnson

Georgia
Parents Educating Parents
Georgia/ARC
1851 Ram Runway, Suite 104
College Park, GA 30337
(404) 761-2745
Director: Mildred Hill

Illinois
Coordinating Council for Handicapped Children
20 East Jackson Boulevard, Room 900
Chicago, IL 60604
(312) 939-3513
Director: Charlotte Des Jardins

Designs for Change
220 South State Street, Room 1900
Chicago, IL 60604
(312) 922-0317
Director: Donald Moore

Indiana
Task Force on Education for the Handicapped, Inc.
833 Northside Boulevard, Bldg. 1-Rear
South Bend, IN 46617-2993
(219) 234-7101
Director: Richard Burden

Iowa
Iowa Exceptional Parent Center
33 North 12th Street
P.O. Box 1151
Ft. Dodge, IA 50501
(515) 576-5870
Director: Carla Lawson

Kansas

Families Together, Inc.
4125 Southwest Gage Center Drive
Topeka, KS 66604
(913) 267-6343
Mailing Address:
P.O. Box 86153
Topeka, KS 66686
Director: Patricia Gerdel

Louisiana

Project PROMPT
United Cerebral Palsy of Greater New Orleans
1500 Edwards Avenue, Suite O
Harahan, LA 70123
(504) 734-7736
Director: Sharon Duda

Maine

Special-Needs Parent Information Network (SPIN)
P.O. Box 2067
Augusta, ME 04330
(207) 582-2504
(1-800) 325-0220 (ME)
Director: Virginia Steele

Massachusetts

Statewide Parent Information Network (SPIN)
Federation for Children with Special Needs
312 Stuart Street, 2nd Floor
Boston, MA 02116
(617) 482-2915
(1-800) 331-0688 (MA)
Director: Artie Higgins

Michigan

Parents Training Parents Project
United Cerebral Palsy Assn. of Metropolitan Detroit
17000 West 8 Mile Road, Suite 380
Southfield, MI 48075
(313) 557-5070
Training Coordinator: Edith Sharp

Citizens Alliance to Uphold Special Education (CAUSE)
313 South Washington Square, Suite 040
Lansing, MI 48933
(517) 485-4084
Director: Eileen Cassidy

Minnesota

Parent Advocacy Coalition for Educational Rights (PACER)
4826 Chicago Avenue, South
Minneapolis, MN 55417-1055
(612) 827-2966
(1-800) 53-PACER (MN)
Directors: Marge Goldberg & Paula Goldberg

Mississippi

Association of Developmental Organizations of Mississippi
6055 Highway 18 South, Suite A
Jackson, MS 39209
(601) 922-3210
(1-800) 231-3721 (MS)
Director: Anne Presley

Montana

Parents, Let's Unite for Kids
Eastern Montana College
Montana Center for Handicapped Children
1500 North 30th Street
Billings, MT 59101-0298
(406) 657-2055
(1-800) 222-PLUK (MT)
Director: Katherine Kelker

Nevada

Nevada Specially Trained Effective Parents (N-STEP)
Nevada Association for the Handicapped
6200 West Oakey Boulevard
Las Vegas, NV 89102
(702) 870-7050
Coordinator: Charlene Rogerson

New Hampshire

New Hampshire Parent Information Center (PIC)
155 Manchester Street
P.O. Box 1422
Concord, NH 03301
(603) 224-6299
Director: Judith Raskin

New Jersey

Involve New Jersey, Inc.
26C 2 East Second Street
Moorestown, NJ 08057
(609) 778-0599
Director: Mary Callahan

Puerto Rican Congress of New Jersey
515 South Broad Street
Trenton, NJ 08611
(609) 989-8888
Director: Jose Morales

New Mexico

P.L. 94-142 Parent Training and Support Program
Protection and Advocacy System
2201 San Pedro, NE
Building 4, #140
Albuquerque, NM 87110
(505) 888-0111
Director: Beatriz Mitchell

Education for Indian Children with Special Needs (EPICS Project)
P.O. Box 788
Bernalillo, NM 87107
(505) 867-3396
Director: Randi Malach

New York

Advocates for Children of New York, Inc.
24-16 Bridge Plaza South
Long Island, NY 11101
(718) 729-8866
Director: Norma Rollins

Parents' Information Group/Parent Training Project
215 Bassett Street
Syracuse, NY 13210
(315) 478-0040
Director: Deborah Olson

Parent Network Center
1443 Main Street
Buffalo, NY 14209
(716) 885-1004
Director: Joan Watkins

North Carolina

Exceptional Children's Advocacy Council
P.O. Box 16
Davidson, NC 28036
(704) 892-1321
Director: Connie Hawkins

PARENTS Project
300 Enola Road
Morganton, NC 28655
(704) 433-2864
Director: Anita Hodges

Ohio

Tri-State Organized Coalition for Persons with Disabilities
SOC Information Center
3333 Vine Street, Suite 604
Cincinnati, OH 45220
(513) 861-2475
Director: Cathy Heizman

Ohio Coalition for the Education of Handicapped Children
933 High Street, Suite 200-H
Worthington, OH 43085
(614) 431-1307
Director: Margaret Burley

Oklahoma

Parents Reaching Out in Oklahoma (PRO-Oklahoma)
United Cerebral Palsy of Oklahoma, Inc.
2701 North Portland
Oklahoma City, OK 73107
(405) 681-9710
(1-800) PL9-4142
Director: Connie Motsinger

Oregon

Oregon COPE Project
(Coalition in Oregon for Parent Education)
999 Locust Street, NE, #42
Salem, OR 97303
(503) 373-7477
Director: Cheron Mayhall

Pennsylvania

Parents Union for Public Schools
401 North Broad Street, Room 916
Philadelphia, PA 19108
(215) 574-0337
Director: Christine Davis

Parent Education Network
240 Haymeadow Drive
York, PA 17402
(717) 845-9722
Director: Louise Thieme

Puerto Rico

Associacion de Padres ProBienestar de Ninos Impedios de PR, Inc.
Box 21301
Rio Piedras, PR 00928
(809) 765-0345
(809) 763-4665
Director: Carmen Selles Vila

South Dakota

South Dakota Parent Connection
330 N. Main Avenue, Suite 301
Sioux Falls, SD 57118-4813
(605) 335-8844
Director: Judie Roberts

Texas

Partnerships for Assisting Texans with Handicaps (PATH)
Parents Resource Network, Inc.
6465 Calder Avenue, Suite 202
Beaumont, TX 77707
(409) 866-4726
Director: Janice Foreman

Utah

Utah Parent Information Center (PIC)
4984 South 300 West
Murray, UT 84107
(801) 265-9883
Director: Jean Nash

Vermont

Vermont Information and Training Network (VITN)
Vermont/ARC
Champlain Mill, #37
Winooski, VT 05404
(802) 655-4016
Director: Connie Curtin

Virginia

Parent Education Advocacy Training Center
228 South Pitt Street, Room 300
Alexandria, VA 22314
(703) 836-2953
Director: Winifred Anderson

Washington

Parents Advocating Vocational Education (PAVE)
6316 South 12th Street
Tacoma, WA 98645
(206) 565-2266
(1-800) 5-PARENT (WA)
Director: Martha Gentili

Wisconsin

Parent Education Project
United Cerebral Palsy of SE Wisconsin
230 West Wells Street
Milwaukee, WI 53203
(414) 272-4500
Director: Liz Irwin

National Resources

NaDSAP

National DIRECTION Service Assistant Project (NaDSAP)
The National Parent CHAIN
933 High Street, Suite 106
Worthington, OH 43085
(614) 431-1307
Director: Donna Owens

NaDSAP is a technical assistance project aimed at helping states design, develop and implement state-wide systems of DIRECTION services.

STOMP

Specialized Training of Military Parents (STOMP)
Georgia/ARC
1851 Ram Runway, Suite 104
College Park, GA 30337
(404) 767-2258
Coordinator: Kathy Mitten

Specialized Training of Military Parents (STOMP)
12208 Pacific Highway, SW
Tacoma, WA 98499
(206) 588-1741
Program Manager: Heather Hebdon

STOMP provides information and training to military families with children who have special educational needs. The project assists parents in networking within the military and civilian community. Services are provided to families both in the United States and overseas.

TAPP

Technical Assistance for Parent Programs (TAPP)
312 Stuart Street, 2nd Floor
Boston, MA 02116
(617) 482-2915
Director: Martha Ziegler

TAPP provides technical assistance for programs that work with parents of children with disabilities. Technical assistance is provided through the following four regional centers:

New Hampshire Parent Information Center (PIC)
155 Manchester Street
P.O. Box 1422
Concord, NH 03301
(603) 224-6299
Director: Judith Raskin

Parent Advocacy Coalition for Educational Rights (PACER)
4826 Chicago Avenue, South
Minneapolis, MN 55417-1055
(612) 827-2966
(1-800) 53-PACER (MN)
Directors: Marge Goldberg & Paula Goldberg

Parents Educating Parents
Georgia/ARC
1851 Ram Runway, Suite 104
College Park, GA 30337
(404) 761-2745
Director: Mildred Hill

Parents Advocating Vocational Education
6316 South 12th Street
Tacoma, WA 98645
(206) 565-2266
(1-800) 5-PARENT (WA)
Director: Martha Gentili

For information regarding these programs contact:

U.S. Department of Education
Office of Special Education and Rehabilitative Services (OSERS)
Office of Special Education Programs
Division of Personnel Preparation
Switzer Building, Room 4620
400 Maryland Avenue, SW
Washington, DC 20202
(202) 732-1032
Contact: Jack Tringo, Project Officer

TECHNICAL ASSISTANCE FOR PARENT PROGRAMS (TAPP) REGIONAL CENTERS
(And Areas Served)

NORTHEAST REGIONAL CENTER

Parent Information Center
155 Manchester Street
P.O. Box 1422
Concord, NH 03301
Judith Raskin, Director
Linda Klausmeyer, TA* Coordinator
(603) 224-6299

Area Served

Connecticut
Delaware
Maine
Maryland
Massachusetts
New Hampshire
New Jersey
New York
Pennsylvania
Puerto Rico
Rhode Island
Vermont
Washington, D.C.

MIDWEST REGIONAL CENTER

PACER Center, Inc.
4826 Chicago Avenue, South
Minneapolis, MN 55417
Paula Goldberg, Co-Director
Polly Edmunds, TA Coordinator
(612) 827-2966

Area Served

Colorado
Illinois
Indiana
Iowa
Kansas
Kentucky
Michigan
Minnesota
Missouri
Nebraska
North Dakota
Ohio
South Dakota
Wisconsin

WEST REGIONAL CENTER

Washington State PAVE
6316 South 12th Street
Tacoma, WA 98465
(206) 565-2266
Martha Gentili, Director
Joanne Butts, TA Coordinator

Area Served

Alaska
American Territories
Arizona
California
Department of Defense
Dependent Schools
Hawaii
Idaho
Montana
Nevada
New Mexico
Oregon
Texas
Utah
Washington
Wyoming

SOUTH REGIONAL CENTER

Parents Educating Parents
Georgia Association for
Retarded Citizens
1851 Ram Runway, #102
College Park, GA 30337
(404) 761-2745
Mildred Hill, Director
Carla Putnam, TA Coordinator

Area Served

Alabama
Arkansas
Florida
Georgia
Louisiana
Mississippi
North Carolina
Oklahoma
South Carolina
Tennessee
Virginia
West Virginia

* TA stands for Technical Assistance

NOTES

ATTACHMENT C

References for Families

Books

Featherstone, H., A Difference in the Family: Living with a Disabled Child. 1981. New York: Penguin Books.

A book about the anger, fear, frustration, and joy a family experiences in caring for a child with handicaps, based on the author's own experiences with her severely handicapped son.

Fewell, R., & Vadasy, P., Eds., Families of Handicapped Children: Needs and Supports Across the Life Span. 1986. Austin, TX: Pro-Ed. (Available from Pro-Ed, 5341 Industrial Oaks Blvd., Austin, TX 78735.)

A book describing the many issues facing families of special needs children and the experiences of family members in their roles within the family "system." Provides information on support systems outside the family, including school-based, medical, and community services, and support from one's own religious community.

Goldfarb, L.A., Brotherson, M.J., Summers, J.A., & Turnbull, A., Meeting the Challenge of Disability or Chronic Illness - A Family Guide. 1986. Baltimore: Paul H. Brookes Publishing Co. (Available from Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD, 21285-0624.)

A book covering the issues faced by families who must care for a family member with a handicap or serious illness. Discusses in detail the common problems that these families face, suggests ways families can get needed support based on their strengths and needs, and offers advice on how each family can define and take steps to solve the unique problems it faces. Contains an extensive resource section, and practical exercises for defining problems, for assessing family needs, strengths, and weaknesses, and for solving problems.

Thompson, Charlotte E., Raising a Handicapped Child: A Helpful Guide for Parents of the Physically Disabled. 1986. New York: William Morrow and Co., Inc.

A practical guide for parents new to the issues of disabilities or chronic illness. Offers suggestions on how to make decisions under pressure, find helpful professionals, cope with the costs of raising a child with handicaps, handle progressive disease and death, and how to survive parenting a special needs child. Includes extensive references and resources sections.

Tingey-Michaelis, C., Handicapped Infants and Children: A Handbook for Parents and Professionals. 1983. Austin, TX: Pro-Ed. (Available from Pro-Ed, 5341 Industrial Oaks Blvd., Austin, TX 78735.)

A book about long-term, home care of children with handicaps. Contains practical information on meeting the needs of a child with handicaps with minimal disruption to the family.

Turnbull, Ann P. & Turnbull, H. Rutherford, Families, Professionals and Exceptionality: A Special Partnership. 1986. Columbus, Ohio: Merrill Publishing.

A book that addresses the issues of the unique and interdependent roles that families and professionals assume in caring and advocating for individuals with handicaps.

Other Printed Materials

Parents Guide to the Development of Pre-School Handicapped Children: Resources and Services. October, 1984. No. 84-5. (Available from National Library Service for the Blind and Physically Handicapped, The Library of Congress, Washington, D.C. 20542.)

A listing of national organizations and producers and distributors of materials and services designed to assist parents in promoting their child's development in the early years.

Parent Helper - Handicapped Children Birth to Five. Maryland State Department of Education. 1982. (Order from Superintendent of Documents, U.S. Government Printing Office, Washington, D.C. 20402.)

Handbooks on Socialization, Communication, Cognition, and Motor Development.

Parent Resource Directory (For Parents and Professionals Caring for Children with Chronic Illness or Disabilities). 2nd edition. January, 1988. (Available from the Association for the Care of Children's Health, 3615 Wisconsin Ave., N.W., Washington, D.C. 20016. Phone (202) 244-1801 or 244-8922.)

A directory for parents and professionals to use to network and collaborate with others who care for or provide services to children having special health care needs. A resource for helping both parents and professionals develop partnerships at the state and local levels.

Selected Readings for Parents of Preschool Handicapped Children (A Bibliography). July, 1986. No. 86-1. (Available from National Library Service for the Blind and Physically Handicapped, The Library of Congress, Washington,D.C. 20542.)

A bibliography of a representative selection of books and periodicals in the area of preschool handicapped children, with emphasis on publications since 1979.

The Exceptional Parent (A magazine published eight times a year for parents, individuals, organizations, librarians, schools and agencies. (Available from The Exceptional Parent, 605 Commonwealth Ave., Boston, MA 02215. Phone: (617) 536-8961. Also available at some book stands.)